MY DEATH, MY DECISION

Terminally Ill Adults (End of Life) Bill

Legislative Consent Motion

Senedd Health and Social Care Committee Call for Evidence

My Death, My Decision

26th August 2025

Response from My Death, My Decision (MDMD)

Summary

My Death, My Decision is a grassroots organisation that campaigns for laws across the United Kingdom to allow those who are terminally ill or intolerably suffering from incurable conditions the option of a legal, safe, and compassionate assisted death.

My Death, My Decision (MDMD) supports a Legislative Consent Motion for the Terminally Ill Adults (End of Life) Bill.

As an organisation, we focus on the individual's experience and aim to ensure that any legislation on assisted dying has that person's journey at its heart.

We are firmly committed to proposing an evidence-based law that would balance individual choice alongside robust safeguards for the most vulnerable.

We have submitted evidence to legislative work in Scotland, Jersey, the Isle of Man, and the Republic of Ireland as well as the UK Parliament Health and Social Care Committee's inquiry into assisted dying. We also submitted evidence to the Westminster Terminally Ill Adults Bill Committee. We provided oral evidence to the Nuffield Council of Bioethics Citizens' Jury on Assisted Dying, and have presented evidence to other legislatures.

Our views on LCM relevant clauses

This evidence is presented in response to the Senedd Health and Social Care Committee's call for evidence in the letter to stakeholders. However, since then, we recognise that the supplementary Legislative Consent Motion has been laid following changes to the Bill at Report Stage. We will address those changes as part of our evidence. Where merely the clause number has changed, we will reference this at the start of each section.

Clause 37: Guidance about the operation of the Act **(Now Clause 40)**

Clause 37 of the Bill requires the Chief Medical Officer (CMO) for Wales to prepare and publish guidance about the operation of the Act. Before making guidance, the CMO must consult with relevant individuals and groups, including people with learning disabilities, and ensure the guidance is practical and accessible.

Following Report Stage of the Bill, changes were made to this clause, which now sits in the Bill as Clause 40. This requires Welsh Ministers to issue guidance relating to the operation of the Act in Wales, about matters within devolved competence. The Welsh Ministers must consult

with specified persons before issuing guidance, including the Chief Medical Officer for Wales. This clause imposes requirements on the Welsh Ministers to publish any guidance they issue and to have regard to specified matters when preparing guidance.

Q1: What are your views on these proposals?
We strongly support the requirement that Welsh Ministers prepare and publish practical, accessible guidance following consultation with the Chief Medical Officer (CMO) for Wales and relevant individuals and groups, including people with learning disabilities and those with protected characteristics. This requirement is essential to ensure safe, effective, and inclusive implementation.

Q2: Are these proposals sufficient to ensure that the CMO can effectively oversee implementation?
Under the revised Bill, the responsibility for preparing guidance now lies with Welsh Ministers and the Secretary of State, not the CMO for Wales. However, we firmly support that the CMO for Wales must be consulted when guidance is being designed.

We would recommend ensuring the CMO for Wales has a leading role in developing the guidance, including through convening medical networks. We would also recommend explicitly including the following in the guidance:

- Standardised clinical pathways for assessments and eligibility decisions,
- Guidance for clinicians in rural or resource-limited settings,
- Information-sharing protocols between services and regulators.

Q3: Do the proposals provide sufficient safeguards to protect vulnerable individuals?
Yes. Ensuring consultation with people with learning disabilities strengthens protections and inclusivity. Mandatory training on domestic abuse further adds to this, and could be explicitly referenced in the guidance. The legislation is also strong on safeguarding professionals who wish to 'opt-out'.

International evidence further suggests that well-drafted guidance underpins safety:

- In Victoria, Australia such guidance led to clear safeguards and consistent delivery. A detailed review found assisted dying operating safely and compassionately, with improvements across system preparedness, workforce capability, and public support
- In Oregon, the low usage rates and high palliative care involvement suggest robust regulation and responsible practice. Over 25 years, only around 0.8% of total deaths were via assisted dying, with strong hospice integration and no evidence of misuse.

Recommendation: In preparing guidance, as well as engaging with relevant demographic groups and professional bodies, Welsh Ministers should engage with the Disability Advisory Board appointed by the Voluntary Assisted Dying Commissioner.

Clause 39(1),(2),(5) and (6): Voluntary Assisted Dying Services: Wales **(Now Clause 42)**

Clause 39 allows the Welsh Ministers to make regulations to support how voluntary assisted dying services work in practice in Wales. These regulations can be tailored to different situations (such as hospitals or care homes), and may include technical or transitional arrangements.

Q4: What are your views on enabling Welsh Ministers to regulate the structure, management, and delivery of services?
The absence of an operational model yet is a challenge, as is considering how services may be delivered within a Welsh context. However, the regulations are clear on defining who makes the regulations and who approves them. We consider they are robust in enabling Welsh Ministers to develop services in line with Wales's health system priorities and tailored for different settings, helping to address different experiences for e.g hospitals, care homes, rural communities.

Q5: How will these regulations (if approved) impact current palliative care practices in Wales?
The specification and commissioning framework for hospices (due to go live in April 2026) will provide a valuable standard to allow assisted dying to complement and enhance palliative care services.

We welcome the view that delivery of palliative care should be seen independently of assisted dying, with no case for diversion of funding from such a critical health service.

Further, we expect these regulations to complement and enhance palliative care. International experience suggests assisted dying laws often lead to improvements in palliative care, as outlined by the 14-month inquiry into assisted dying by the UK Parliament's Health and Social Care Committee. Some examples are below:

- In **Victoria**, 81% of assisted dying participants were already receiving palliative care; the law led to deeper integration and earlier end-of-life conversations. Many died in their preferred setting, including home or care facilities.
- In **Canada**, the use of palliative care has risen by almost 10% across the population, which researchers say is almost certainly the fastest rate of growth of palliative care in Canadian history.
- In **Colorado,** 84.9% of participants were in hospice care when they died, reinforcing the linkage between assisted dying and palliative services.
- In **Quebec,** a right to palliative care was mandated, which prompted more investment and earlier conversations about end-of-life care. 75% of participants received palliative care. (A further 14.7% did not require palliative care, and 2.3% had care available but did not access it.) Assisted dying services are often delivered by palliative care physicians in Quebec, leading to a holistic and patient-centred model.
- Provision of palliative care also improved in **Oregon**, with some hospitals reporting a 20% increase in referrals in the first 18 months after the assisted dying vote, following changes to healthcare plan eligibility as a result of the vote. From 1998-2020, on average 91% of those requesting an assisted death were enrolled in palliative care, rising to 92% in 2022. People who request assisted dying are more

likely to be in hospice and to have enrolled earlier than the average terminally ill patient.

- The Nuffield Trust examined 15 jurisdictions where assisted dying is legal and found that 75% or more people accessing assisted dying were reported to be receiving palliative care in 2023.

Regardless, it is important to note that palliative care sadly cannot relieve pain for all. In 2024, the Office of Health Economics found that, across the UK, over 7,000 people per year die with no pain relief in their last three months, even with the highest possible levels of palliative care.

One consequence is that, each year, a significant number of people with terminal illnesses try to take their own lives in ways that are often violent, unpredictable, and distressing. A study by the Office of National Statistics found that adults diagnosed with a terminal illness are twice as likely to die by suicide. Legal assisted dying would remove the need for these distressing attempts.

Therefore, the option of an assisted death is crucial to many, even those who do have good palliative care.

Furthermore, just having the option of an assisted death can have a positive impact on those facing the end of life.

In countries with assisted dying laws, people who are eligible are greatly comforted by this being available if they need it, even if they do not opt for it themselves. As philosophy Professor Ben Coburn writes, '*In the face of ill health and decline, it can be transformative for someone to know that they have a (potentially) acceptable escape, even if – suitably empowered and encouraged by that knowledge – they choose not to take it.*'

Similarly, a British Medical Association briefing states, '*The existence of legislation allowing assisted dying brings reassurance and peace of mind for many people with terminal illness and their loved ones, even though only a small percentage actually use it when the time comes.*'

The availability of legal assisted dying, in those societies where it exists, helps far more people than the few who ultimately opt for it. For many sufferers, having a 'backup plan' that is under their control substantially eases the anxiety they experience regarding the potentially uncontrolled pain and indignity of terminal and progressive illnesses. In this regard, access to assisted dying is complementary to palliative care.

Recommendation: Welsh regulations should ensure seamless integration between assisted dying and palliative care, as well as shared training.

Recommendation: As there will be reviews of palliative care by the Secretary of State at both 12 months and five years after the Act passing, the Welsh Government should contribute to those reviews to ensure the Welsh palliative care experience is properly reflected.

Clause 45: Monitoring by Commissioner (Now Clause 49)

Clause 45 requires the Voluntary Assisted Dying Commissioner (appointed by the Prime Minister) to monitor the operation of the Act, investigate and report to an appropriate national authority on any matter connected with the operation of the Act which the appropriate national authority refers to the Commissioner, and submit an annual report to each appropriate national authority on the operation of the Act.

Q6(a): What are your views on allowing Welsh Ministers to refer matters to the Commissioner?
The legislation has been strengthened by moving the responsibility from the CMO to the Commissioner. We support that Welsh Ministers may refer matters to the Commissioner. It ensures devolved oversight, giving Welsh Ministers a voice in monitoring the service and responding to Welsh-specific concerns, without undermining the UK-wide nature of the Commissioner role.

Q6(b): What are your views on requiring the Commissioner to consult the CMO for Wales in annual reports?
This is a necessary and welcome provision. It ensures that Welsh-specific experiences, service models, and population needs are reflected in national oversight.

Q6(c): What are your views on requiring Welsh Ministers to publish and respond to the Commissioner's annual report?
We support this as a transparency and accountability measure. It aligns with good governance principles and ensures that the Senedd and the public are kept informed of how the Act is working in practice in Wales. This also supports the Welsh Ministers in continuing to deliver on their obligations that the legislation remains workable.

Clause 47(4): Provision of Information in English and Welsh (Now Clause 51: Provision about the Welsh language)

Clause 47 requires any service, report, declaration or certificate of eligibility provided under the Act to a person seeking assistance to end their own life must be in the persons first language, if that language is English or Welsh and, if neither of those languages is their first language, must be in their preferred language of English or Welsh.

Following Report Stage of the Bill, changes were made to this clause, which now sits in the Bill as Clause 51. This places a duty on the Welsh Ministers to make provisions to ensure that those wishing to communicate in Welsh are able to do so, including for all written reports. This clause also requires consultation between the Secretary of State and the Welsh Ministers before the Secretary of State makes regulations about the form of documents, such as the declarations or final statements, to be available in Welsh.

Q7(a): Do you agree that services and documents must be provided in a person's first language if English or Welsh, and otherwise in their preferred language of English or Welsh?
Yes. We fully support these provisions to ensure informed consent and equitable access. It

reflects, for example, the Welsh Language Measure 2011, in which the NHS in Wales has a statutory duty to deliver services to the public in both Welsh and English. Language should never be a barrier to exercising one's legal rights at the end of life.

Q7(b): What are your views on requiring Senedd approval for any Welsh-language-related regulations?
This is appropriate. It aligns with Wales's devolved language policy and ensures democratic legitimacy.

Clause 50(1), (2), (5) and (6): Regulations **(Now Clause 54)**

Clause 39 allows the Welsh Ministers to make regulations to support how voluntary assisted dying services work in practice. Clause 50 provides that such regulations must be approved by the Senedd before they can take effect.

Q8: What are your views on the proposed procedure for regulations, and whether it provides appropriate Senedd oversight?
We support this. Senedd approval for regulations is a proportionate and necessary safeguard given the ethical importance of the issue and the need to ensure consistency across the devolved health system. It also ensures that public and stakeholder voices can continue to be reflected as regulations evolve. This could be enhanced with public consultation.

We would recommend that any preparatory work gets underway as soon as possible to ensure development of Welsh regulations does not fall behind those being prepared in the UK Parliament and, subsequently, that access for Welsh residents is not delayed. This is particularly important in the context of a new Senedd in 2026, with new members potentially approaching this legislation for the first time. Work must be done to ensure all new MSs have the information and tools they need to take the legislation forward in Wales, if it does become law in Westminster.

As far as possible, the Welsh Government may wish to coordinate with the UK Government to reduce burdens on Welsh residents (particularly in border communities) should regulations evolve in a way that makes access to assisted dying substantially different in Wales than England. For example, if Welsh NHS regulations are not passed by the Senedd, this could lead to an unjust system where those living in Wales may only be able to access an assisted death through private provision, whilst those in England could get access through the NHS. That would mean only those who can afford private care in Wales would have meaningful control at the end of life, while others are denied the compassion and dignity they deserve, unless they are able to travel over the border to England. With average incomes in Wales lower than in England and Scotland, the development of a "private only" model in Wales could further broaden existing health inequalities.

We must ensure that terminally ill people who are already facing substantial hardship do not have to navigate additional complexity in carrying out their end of life wishes.

Recommendation: Though there is no statutory requirement to do so, Welsh Ministers should also consider a public consultation on the necessary regulations to ensure they are both robust and would allow the service to be delivered in the least burdensome way for those seeking an assisted death.

Recommendation: Commence preparatory work to ensure a Welsh perspective is captured to better inform the development of the draft regulations, e.g. usual assessments and public consultation in line with work already undertaken by Westminster. This should be completed as soon as possible to ensure the new Senedd members elected in May 2026 are well informed to carry out their duty to take the legislation forward in Wales.

Clause 54(6), (8) and (9): Commencement **(Now Clause 58)**

Clause 54 deals with the commencement of the Act.

Following Report Stage of the Bill, changes were made to this clause, which now sits in the Bill as Clause 58.

Q9: What are your views on allowing Welsh Ministers to decide commencement dates (subject to Senedd approval)?
We agree with this proposal. It allows Wales to ensure systems are in place - including workforce training, public awareness, translation of materials, and referral pathways - before the law is operational. This supports safe and consistent delivery.

We recognise the concern over the system change is real and significant. This is further underlined by the current lack of an operational model and possible capacity concerns in the NHS to bring the legislation forward.

However, we would urge the swiftest possible progress, recognising that the four-year implementation period in the Bill is a backstop and not a goal. Every month without implementation is a month where terminally ill people do not have the choice they deserve.

It is important to note that no other jurisdiction in the world has taken longer than three years to implement a democratically passed assisted dying law, and only one has taken longer than 19 months, and that was Oregon, due to legal challenges.

Some of the autonomous regions in Spain established a working law just three months after the national parliament passed assisted dying legislation, including oversight panels similar to the model proposed in this Bill – Spain being the only other jurisdiction to have this model. Regional implementation timelines of the panels varied between three months and a year.

More locally, approved proposals in Jersey include an implementation period of 18 months, and of two years in the Isle of Man.

Extensive training, guidance and codes of practice already exist internationally, in jurisdictions with very similar legislation. We can safely draw from it to reduce an unnecessarily long implementation period.

Q10: Is the procedure appropriate?
Yes, requiring Senedd approval ensures that readiness is scrutinised and democratically accountable.

Q11: What are your views on the implications of different start dates in England and Wales?
We are concerned that staggered start dates could cause some public confusion, particularly for those living in border communities. We recommend proactive coordination between the UK and Welsh Governments with efforts to align commencement dates, if possible, and clear communication for patients and professionals on when and where the law applies.

Recommendation: Welsh Government should develop joint public messaging strategies and referral protocols with UK Government colleagues and NHS England to ensure clarity across borders.

Conclusion

My Death, My Decision supports the Legislative Consent Memorandum and the devolved provisions it outlines. We believe the proposals:

- Provide appropriate oversight and regulatory powers to Welsh Ministers,
- Respect the Welsh health and language context,
- Embed strong safeguards and transparency,
- Align with international best practice on assisted dying.

More broadly, we strongly support the case for assisted dying through a clear, legal framework in Wales. It is an affirmation of clear and positive values that are capable of being shared by people of all different backgrounds and beliefs:

- **Dignity**: Passing the Bill will give terminally ill adults the choice and dignity of a compassionate death within the law. People with terminal illnesses will gain peace, knowing that if their suffering becomes too great, they have a choice.
- **Autonomy**: It's your death, it should be your decision. Just as you already have a right to refuse treatment, no one else should have the right to stop you from choosing a safe and painless death.
- **Compassion**: We all participate in the suffering of those we love. A clear law will allow families to focus on quality time together that will never come again instead of distress.

The current situation for many people is indefensible:

- **Pain**: While most people die peacefully and naturally, a small but significant minority experience extreme suffering. The Office of Health Economics estimates that 20 people a day will die in pain, even with the best possible palliative care.
- **Inequality**: Only those with enough money to spare, as well as the physical ability to travel, are able to have assisted deaths abroad in Switzerland. More than one person a week ends their life abroad.
- **Suicide**: People who are diagnosed with a terminal condition are twice as likely to die by suicide, and those diagnosed with a neurodegenerative condition are 100x times more likely to do so. People are voluntarily stopping eating and drinking, leading to uncomfortable and prolonged dying.

Assisted dying internationally is safe, dignified and supported by the public:

- **Introduction of safeguards:** Coercion and abuse thrive in the darkness, in the absence of safeguards and scrutiny. Legalising this would introduce safety measures and checks.
- **Peaceful death:** The life-ending medication used by the Swiss centre DIGNITAS is dignified and peaceful. Their evidence to the Terminally Ill Adults Bill Committee said: 'Every patient ingesting [the] lethal dosage passed away, with no instances of regaining consciousness.'
- **Consistent public support:** Public opinion polls in jurisdictions where assisted dying is legal, including Australia, Oregon, Canada and Switzerland, show overwhelming public support.

We hope our contribution has been useful, and we would be pleased to offer further assistance or evidence to support the Committee's scrutiny.